

# Understanding the perceived impact and value of research advocacy initiatives for colorectal cancer

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## Research

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# Abstract

## Background

Research advocacy utilizes patient insight to progress research, ensuring that patient values remain a priority. It is integral to inform activities such as designing clinical trials, providing perspectives on Institutional Review Boards (IRB's), and reviewing research grants. As a leader in colorectal cancer (CRC) advocacy, Fight Colorectal Cancer (Fight CRC) developed a formal research advocacy training program in 2015 with the goal of preparing CRC advocates to become the most educated patient voice at the research table.

## Methods

To understand the effectiveness of a research advocacy training program and subsequently research advocacy as a whole, Fight CRC distributed online questionnaires between December 2018 and July 2019 to oncology professionals who had previously worked with Fight CRC research advocates, including physicians, program directors, and consumer review administrators. A questionnaire was also disseminated to Fight CRC research advocates.

## Results

In total, twenty-six stakeholders participated and 89% agreed/strongly agreed that there was value in having the patient voice in research. Respondents reported that advocates provide a perspective that would not otherwise be considered in the research process. Fourteen research advocates participated in the survey and the majority indicated that the research advocacy program equipped them to sit on panels and provide effective insight. All research advocates believed that their patient insight is taken seriously by the research community.

## Conclusion

In order for research advocacy to have a significant impact and a high perceived value on research, it is important to establish an effective training program to support adult learning. In addition, it is necessary for researchers to understand how advocates can positively influence their work, and how the scientific community can engage with and leverage research advocacy to its fullest potential to improve scientific research, delivery of care, and quality of life for patients with cancer.

## Introduction

The idea of patient centricity has been defined as, "putting the patient first in an open and sustained engagement of the patient to respectfully and compassionately achieve the best experience and outcome

for that person and their family.”<sup>1</sup> This concept is not new, and now more than ever, pharmaceutical companies, healthcare professionals, advocacy organizations and cancer organizations are leveraging the voice, thoughts, values, preferences, strengths and weaknesses of the patient to excel research, ensuring that patients, the consumers of healthcare, are actively involved.<sup>2</sup> Increasingly, regulatory agencies are requiring the involvement of patients, caregivers and champions of a specific disease type along the research continuum. Also known as research advocates, these individuals in their respective fields are integral to activities such as informing clinical trial designs, providing insight on Institutional Review Boards (IRB) and voting on research grants.

In the early 2000s, it was apparent that the non-scientific viewpoint was not at the center of research. As a leader in colorectal cancer (CRC) advocacy, Fight Colorectal Cancer’s (Fight CRC) founder Nancy Roach, along with the late CRC survivor Kate Murphy, informally created what is now Fight CRC’s Research Advocacy Training and Support (RATS) program. The RATS program was formalized in 2015 with the goal of training CRC advocates to become the most educated patient voice at the research table, representing the collective patient voice. After getting involved in regulatory advocacy, Roach realized that there were very few “squeaky wheels” in cancer research, and research advocacy could impact the community as a whole. Fight CRC also looked to those already in the field, specifically in breast cancer, and predicated the RATS program based on the benefits it was having in other disease types.

Since the creation of the RATS program, over forty CRC research advocates have completed the foundational training. There are currently over twenty active research advocates who serve on panels with organizations and governmental agencies such as the Department of Defense (DoD) Peer Reviewed Cancer Research Program (PRCRP), the Southwest Oncology Group (SWOG), the Patient Centered Outcomes Research Institute (PCORI), the National Cancer Institute (NCI) and the American Society of Clinical Oncology (ASCO), as well as state-based cancer programs, local institutional review boards, and industry partner advisory boards.

With the uptick in the use of research advocates in oncology, it becomes critical to contribute to the body of evidence based on lessons learned, and understand and define the efficacy of a research advocacy training program and subsequently, research advocacy as a whole. This includes the perceived impact and value, as well as gaps and opportunities to enhance the ability of research advocates to effectively serve in the research process. As the RATS program enters its fifth year as a formal and sustainable training program, it is necessary to evaluate the perceived value of both the program and research advocacy as a whole, and its impact on CRC research.

## **Methods**

### **Engaging Stakeholders Utilizing Research Advocates**

To understand the perceived value of research advocacy from the perspective of professionals in oncology, Fight CRC distributed an online questionnaire from December 2018 to July 2019 consisting of

14 questions to researchers, oncologists, advocacy program directors, Fight CRC's Medical Advisory Board (MAB), and members of Fight CRC's Early Age Onset (EAO) and Immunotherapy (IO) working groups. Members of Fight CRC's Patient Education and Research team analyzed the results utilizing SurveyMonkey® and Microsoft Excel worksheets.

## **Bringing in the Patient Voice**

Fight CRC's Patient Education and Research team also evaluated the perspective of current Fight CRC research advocates using an online questionnaire consisting of 11 questions that was distributed between July 2019 and August 2019. The team analyzed results utilizing SurveyMonkey® and Microsoft Excel worksheets.

# **Results**

## **Stakeholder Response Demographics**

A total of 26 stakeholders that have previously or currently work with Fight CRC research advocates participated in the survey. The majority (65.38%) represented academia, followed by the National Institutes of Health (NIH) or the NCI (15.4%), non-profits (11.5%), pharmaceutical companies (4%), and the DoD (4%).

Of those working in academia, 46% self-identified as a Professor, Assistant Professor, or Professor Emeritus. Additional roles included:

- Consumer Reviewer Administrator
- Advocacy Relations Manager
- Associate Group Chair
- Program Directors and Managers
- Medical Doctors

Of the complete responses received, 37% indicated they were part of Fight CRC's MAB, 63% were not part of Fight CRC's MAB.

Figure one represents the different types of events in which respondents have engaged with research advocates. Those who selected "Other" have previously engaged with advocates through events such as committee meetings, guideline development panels and at conferences such as ASCO.

Different activities in which this group of stakeholders engaged with research advocates included:

- Reviewing a role-play script to help educate physicians on how to have a best practice shared decision-making conversation with their CRC patients.

- Developing guidelines in Mismatch Repair (MMR) and Microsatellite Instability (MSI) testing for patients being considered for immunotherapy.
- Providing commentary during meetings on what issues are important to them as patients and caregivers.
- Steering committee/task force reviews which are responsible for reviewing clinical trial protocols for approval.
- Developing an EAO CRC research agenda.
- Reviewing an R01 proposal for clinical trials.
- Serving on peer review panels alongside scientific reviewers to provide their input on the potential impact a proposal may have on the community if successful.

### **Performance of Research Advocates**

On a scale of one to five, with one being completely unprepared, and five being completely prepared, we asked stakeholders to evaluate the research advocates. The average score of respondents was 4.51 out of 5.

Additionally, participants were asked to rate their level of agreement (strongly disagree to strongly agree) on the following statements regarding their interactions with research advocates.

- 89% strongly agreed or agreed that the research advocate was engaged in the discussions at an appropriate level and that the group benefitted and saw the value of having a patient advocate voice.
- 5% strongly agreed or agreed that the research advocate showed up with the right orientation and training to serve in this role as a patient representative.
- 84% strongly agreed or agreed that the research advocate provided a unique perspective that wouldn't have otherwise been captured.
- 100% strongly agreed or agreed that the research advocate was willing to learn and that they would engage with Fight CRC research advocates again.

Responses highlighting how the research advocate contributed to shaping the conversation or leading to change included:

*The input was invaluable in identifying in particular 1) the level of detail some patients may wish to have explained by their physician and 2) phrases that were too technical and needed to be updated to be more clearly understood by patients.*

*The [research advocate] set the tone for an honest, empathetic conversation regarding the realities of living with a cancer diagnosis and how the lives of family members and loved ones are changed following a diagnosis. Additionally [the advocate] brought up multiple ideas for types of educational tools that patients might find valuable.*

We also asked what value the Fight CRC research advocates provide the scientific community and their role in cancer research. Responses included:

*The CRC advocates have not only provided input into CRC, but also in other Gastrointestinal (GI) cancers. They are willing to learn about other cancers and contribute on a wider scale. They have been so essential since we have had many concepts to review in the past six months. They have been contributing and adding value with good written reviews and presenting their reviews on the phone calls with our team.*

*There are two values that I think research advocates will bring to research: (1) constantly reminding those that design and perform research that there are real people who will benefit from their work and (2) pointing out that sometimes what doctors/researchers assume that patients prefer is not actually what patients prefer.*

Areas of improvement for research advocates that the scientific community suggested included better representation of the collective patient experience and not a single person's perspective, preparing ahead of time the message that advocates want to convey, and increased biologic and therapeutic knowledge.

Overall, on a scale of one to five, with one being completely unsatisfied, and five being completely satisfied, the average ranking was 4.68. Additionally, 95% of respondents indicated a 4- or 5-star rating of their engagement with research advocates.

## **Research Advocate Demographics**

Fight CRC's RATS program consists of 21 active and engaged research advocates. Currently, 33.3% are stage III survivors, 33.3% are stage IV survivors, and 33.3% are caregivers. Two of the research advocates who are caregivers are also medical professionals.

A total of 14 research advocates completed the evaluation survey.

In order to understand how the RATS program affected the research advocates' learning experience, we evaluated both change in knowledge and change in confidence. These metrics help measure the contributions of the RATS program on direct outcomes, including the impact of the training program.

The top three topics that advocates increased their knowledge of the most included checkpoint inhibitors (56% increase in knowledge), the gut microbiome (55% increase) and precision medicine (55% increase). The three areas where research advocates gained the most confidence included joining a panel, board or research study as a research advocate (59% increase in confidence), being able to set realistic and timely goals as a research advocate (55%) and representing the collective patient voice as a research advocate (55%).

From the research advocate's perspective, the majority saw the program having value and impact on research. Comments included:

*The RATS program is a great way to get prepared advocates onto panels and other volunteer opportunities which require a knowledgeable patient voice. It provides support and peers to bounce ideas off of. It also provides info regarding open opportunities. All of these things can help push forward research by putting a face to the work researchers do and by helping to increase clinical trial accruals.*

*Experience and training gained from a reliable source. When people note you are a "RATS" member, they know you are in the group of lifelong learning and that you have put time and effort into your advocacy journey. The connections as well as knowledge of our fellow RATS is loaded with experience and knowledge.*

Research advocates were asked to rate how well the RATS program equipped them to sit on panels and provide effective input on a scale from one to ten (one being not well prepared to ten being very well prepared). The average score was 8.4. Additionally, 100% of respondents believed their authentic patient voice has been taken seriously by the research community.

Research advocates identified several gaps in the RATS program which included creating a mentorship program, continuing to grow the use of community tools and resources, additional basic science training and annual in-person meetings.

## **Discussion**

Prior reviews have identified common themes for effective patient centrality, including: "1) authentic and sustained engagement across the research continuum and beyond, 2) clarity in the roles and expectations of all parties engaged in the research, 3) mutual trust and respect, 4) commitment to co-learning and co-production, and 5) access to the appropriate resources, supports and training."<sup>3</sup> It is apparent that for patient engagement to positively impact research, multifaceted approaches are necessary and numerous factors should be considered.

### **Creating a Highly Efficacious Training Program**

In order for research advocacy to have a significant impact and a high perceived value on research, it is important to have a highly efficacious research advocacy training program which can determine the success of research advocates' engagement in the research process. A well designed and executed program will equip research advocates with the necessary tools to successfully work in tandem with the research and medical community. Previous research conducted by Ivlev et. al has shown that online training developed for patients increases both their knowledge and skills to effectively review PCORI research with a patient centric focus.<sup>4</sup> Other organizations have evaluated training programs in the "basic competencies of evidence-based medicine (EBM) for selected and motivated patient and consumer representatives" and found that it is feasible and may have a positive impact on advocacy work.<sup>5</sup>

After conducting an evaluation of the current RATS program, it is clear that Fight CRC's training program prepares research advocates to effectively engage in the research process. Based on feedback from the

research community, the research advocates were very well prepared to engage in scientifically focused conversations, showed up with the right orientation and training, provided a unique perspective and were beneficial to the conversation. From the patient's perspective, the majority increased their scientific knowledge and confidence levels after completing training provided by Fight CRC, agreed that the RATS program equipped them to sit on panels and provide effective input and believed that their authentic patient voice has been taken seriously by the research community.

This type of evaluation feedback from both the research community and research advocates supports the notion that a training program can provide advocates with the skills necessary to engage with the scientific community and can support the opportunity for authentic and sustained engagement across the research continuum.

### **Gaps and Opportunities in Research Advocacy Training**

Based on the areas of improvement suggested by the scientific community and research advocates, several gaps in research advocacy training were identified. Although research advocates indicated that they gained confidence representing the patient voice, the research community indicated that research advocates could continue to improve their skills by better representing a group's experiences rather than a single person's perspective.

This gap is not unique to the RATS program, or even research advocacy in general. Prior research has determined that biases may exist in research advocacy and that patient advocates may not be entirely representative of the collective patient experience. According to researchers it is important to "validate any insight through a variety of other means, such as database analyses or market research."<sup>6</sup>

According to the article titled: "*How Patient Advocacy Helps Advance Cancer Research: A Conversation on Collaboration*" published by ASCO, one of the recommendations to effectively serve as a patient advocate in the research field is to "remain grounded in the patient communities." As a research advocate, "this means working with newly diagnosed patients, attending support groups, and keeping in touch with how today's patients experience medical care and treatment."<sup>7</sup>

An additional gap was the need to increase advocate's knowledge around biology and therapeutic knowledge. According to an evaluation conducted by the Southwest Oncology Group (SWOG) on patient engagement, a primary gap in training included "patient advocates' knowledge regarding clinical trials."<sup>8</sup>

Both of these gaps identified by the research community can be addressed and improved by leveraging the RATS training framework to further implement evidence based, adult learning techniques. Bryan et al. identified essential learning principles in health promotion practice including:<sup>9</sup>

- Adults' previous experience must be respected and built upon.
- Adults need learning approaches that match their background and diversity
- Adults need to be actively involved in the learning process.

We recommend training programs like RATS utilize these principles to address the gaps identified. This can include involving advocates in the development of the training, understanding that each advocate comes from different professional/technical backgrounds. The training must also be comprehensive, and utilize different learning techniques such as role plays, case studies, in-person events and online modules. By providing co-learning and co-production opportunities, access to the appropriate resources, supports and training, these gaps can be addressed.

## **The Impact of Advocacy on Research**

Understanding how research advocacy impacts the scientific field is essential to continue developing effective training programs and improving the ability of research advocates to work with the research community.

Based on the feedback from a diverse community of researchers and advocates, the impact of research advocacy ranges from:

- Identifying the level of detail patients wish to receive about their diagnosis from their physician.
- Updating technical jargon to make research easier to understand for the patient.
- Setting the tone for an honest and empathetic conversation and providing insight not otherwise noted.
- Providing diverse insight from a range of backgrounds.
- Pointing to specific factors that are important to patients and caregivers.
- Increasing clinical trial accruals.
- Shaping outcome measures in clinical trials.

Deverka et. al. argues patient advocates can have a positive impact in research by, “identifying relevant research questions; alerting researchers to barriers or facilitators to enrollment; characterizing end points that matter to patients and may be differentially impacted by treatment; distinguishing informed consent or data collection issues that are unclear or burdensome; facilitating peer discussions to obtain a collective patient perspective; and assisting with dissemination and implementation of study results.”<sup>8</sup> It becomes clear that research advocacy is not just a concept created out of principle, but rather a need that is essential to integrate along the entire cancer continuum to improve health outcomes for patients in the oncology setting.

## **Conclusions and Future Recommendations for the Research Community**

Based on the impact research advocates can have, it is necessary for researchers and the scientific community to understand how advocates can positively influence their work so they may leverage research advocacy to its fullest potential. This includes understanding that “mutual respect is essential, which requires honesty and authenticity. Transparency and commitment from both parties should begin on day one.”<sup>10</sup> Additionally, it is necessary to have, “reciprocal relationships in which both parties

recognize the value of the other.”<sup>11</sup> It is also essential to work with advocates from an array of backgrounds and communities to understand the entire patient experience. Hickey et al. argues, “There are often power differentials between the public and researchers. This is particularly so when the focus is on groups, perhaps considered as marginalized or seldom heard.”<sup>11</sup> Not only are there opportunities for research advocacy training programs to improve the value of research advocacy, but opportunities for the research community as well. Identifying these nuanced factors can continue to influence the positive impact research advocacy can have within the research community, including but not limited to contributing to scientific research and improving care delivery and quality of life for patients with cancer.

## **Abbreviations**

Fight Colorectal Cancer (Fight CRC)

Colorectal Cancer (CRC)

Institutional Review Boards (IRB)

Research Advocacy Training and Support (RATS)

Department of Defense (DOD)

Peer Reviewed Cancer Research Program (PRCRCP)

Patient Centered Outcomes Research Institute (PCORI)

National Cancer Institute (NCI)

National Institutes of Health (NIH)

American Society of Clinical Oncology (ASCO)

Medical Advisory Board (MAB)

Mismatch Repair (MMR)

Microsatellite Instability (MSI)

Early Age Onset (EAO)

Gastrointestinal (GI)

Evidence Based Medicine (EBM)

Southwest Oncology Group (SWOG)

## Declarations

### ***Ethics approval and consent to participate***

*Not applicable*

### ***Consent for publication***

*Not applicable*

### ***Availability of data and materials***

*The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.*

### ***Competing interests***

*The authors declare that they have no competing interests.*

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### ***Authors' contributions***

*RG, AD, and SW conducted initial survey development and analysis. RG, AD, SW, AQ, and NR all contributed to manuscript development and review.*

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## Figures

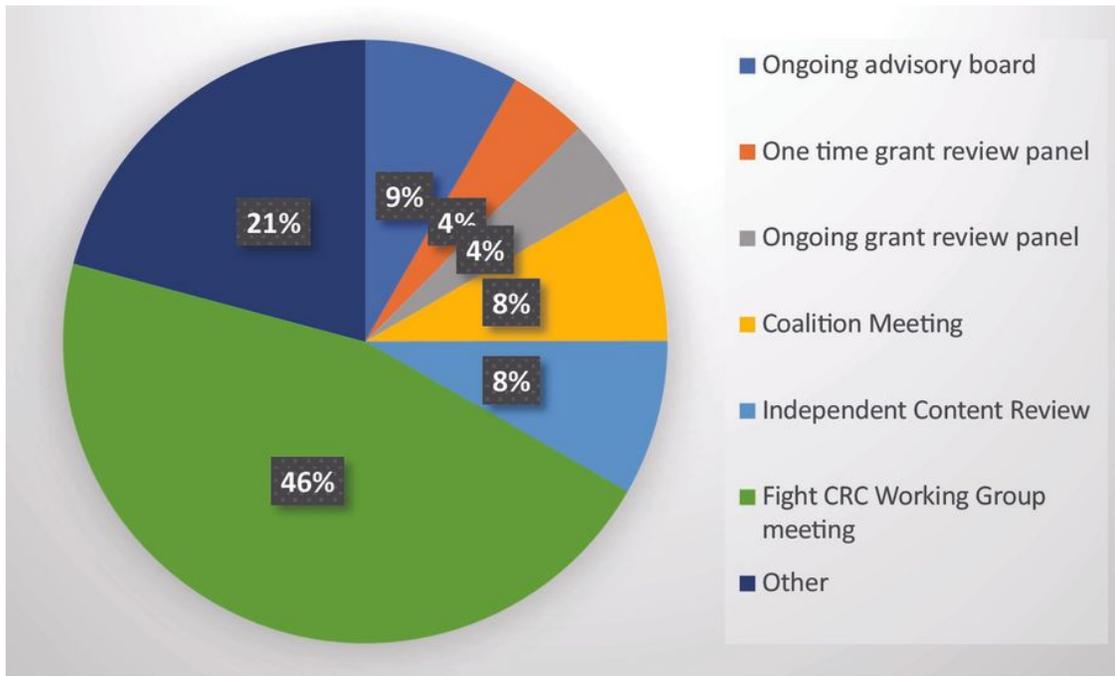


Figure 1. Types of events in which stakeholders have engaged with research advocates

**Figure 1**

Types of events in which stakeholders have engaged with research advocates